Family Caregivers' Perceptions of Caring for Older Persons in the Palliative Care Stage at Home

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Abstract: Palliative care at home for older people in the family context is one of the challenges globally and in Thai society nowadays. Existing palliative care models are not suitable for older people because they need both palliative care and geriatric care, and care is different from younger people because of the nature and duration of illness conditions during older age. Therefore, many family caregivers exert significant burden, responsibility and care tasks for their loved ones and perform a central part of the total care tasks. This study aimed to explore the family caregivers' perceptions of caring for older people in the palliative care stage at home. This study used a descriptive qualitative design with semi-structured interviews and participatory observation of 10 family caregivers. The caregivers cared for older people in Hat Yai, Songkhla Province, southern Thailand. Data were analyzed using content analysis. Two themes were identified of family caregivers' perceptions: 1) recognizing limitations in the ability to provide care and 2) feeling burdened by caregiving. The findings enhance the understanding of healthcare providers and the public on the perceptions of family members providing care for older persons with being at the palliative care stage at home. Primary care centers and nursing education should educate and assist nurses to practice appropriate palliative care guidelines to help caregivers in home settings. This will assist nurses with appropriate skills and knowledge to improve service quality and the quality of life of older people and their caregivers.

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Introduction

Globally, advancements in health care services and living standards have resulted in increases in life expectancy and the proportion of older people in populations. The pace of population aging is much faster than in the past, for example, between 2015 and 2050 the proportion of the world's population over 60 years will nearly double from 12% to 22%.[2] In Thailand, the number of people aged 60 and older is expected to grow from 13% in 2020 to 25% in 2060.[3] Higher age is associated with higher morbidity, which in turn affects care dependency and having multiple illnesses and disabilities with consequent higher demands for palliative care.[4]

Nowadays palliative care is included as part of the care pathway of a wide variety of malignant diseases and nonmalignant diseases.[5] There has been a rapid rise of chronic diseases, including cardiovascular diseases, cancers, and respiratory diseases, which continue to be the leading causes of death.[6] Sixty percent of all cancers are diagnosed in people aged 65 years or older.[7] In Thailand, the majority cause of death is cancer in 2018.[8] Currently more than 55 million people live with dementia worldwide, of which nearly 10 million are new cases every year.[9] The number of older adults living with dementia diagnosed in 2017 was 800,000 people in Thailand. These mainly affect older people in the palliative stage beside the inevitable consequences of aging.[8] All of these conditions contribute to the growing need for home-based palliative care.

Literature Review

Providing palliative care at home preserves dignity in the final phase of life. In addition, home-based care allows older people to spend the end-of-life phase in their own homes together with relatives who can offer them a more emphatic level of support[10] and reduce the cost imposed on the health system and re-hospitalization, including promoting continuing care from hospital to home.[11] However, palliative care is provided to only 14% of 40 million people who need this approach and around 78% of them live in countries with low-or moderate-income.[12]

Care for older people at home is often provided by the family and requires a greater need for health care services because older people develop more chronic and/or debilitating conditions.[13] Many family caregivers exert significant responsibility and care tasks to their loved ones and perform a central part of the total care tasks given by society.[14] Their caregiving requires time and energy and is often given without financial compensation.[15] The caregiver provides the older population with a variety of care needs, and this often causes a burden that may be due to mental and physical illness.[16] Tremendous physical and psychological burdens have a substantial impact on a caregiver's normal life.[16] Health care professionals are expected to help family caregivers to understand and assess their own needs as a crucial element of this process.

The World Health Organization (WHO) considers palliative care as a way of improving the quality of life, for it has a holistic view and takes physical, mental, social, spiritual, and economic dimensions into account.[5] In people often have active and dynamic lives until death.[10] This type of care also supports families of people during illness, death, and even after death, and makes bereavement more peaceful and acceptable for families.[5]

In recognition of the shifting trajectory of dying and the inferences for palliative care, the WHO[17] defines the scope of palliative care beyond end-of-life care. The WHO proposes that palliative care is an approach that can be integrated with life-prolonging therapy and should be improved as death draws near.

Populations are growing older because of positive trends in medical treatment[1] as well as improved living conditions. This increase in the older segment of the population reinforces the requirement for nurses, physicians, and healthcare teams to understand the special palliative care requirements of older people.[2] Because of the increase in both life expectancy and the length of time living with illness conditions, there has been rising emphasis on providing supportive care through life-limiting illnesses and at the end of life.[2] However, palliative care services often pay insufficient attention to the complex needs of individuals.

In older people, the palliative stage may be a steady process that is associated with the increasing effects of illness, frailty, and many interacting conditions, rather than a single cause. In many cases, a major medical situation such as sepsis or a fractured hip can cause the elders to move from a state of illness to a terminal state in which death occurs. Lunney and colleague[19] described the patterns of functional decline of illness trajectories as a short period of apparent decline, long-term restrictions with intermittent serious episodes, and prolonged dwindling. The illness trajectory allows practical planning for a "good death." All trajectories lead to death, but that death may be unexpected. Therefore, healthcare providers can make it evident that advanced planning is rational, and can plan for terminal care in regards to the wishes of older people and their families.

Clinical guidelines for palliative care are often applicable to persons with cancer, whereas older people who need palliative care often increase rapidly from being independent to having multiple illnesses and disabilities.[1,2] Therefore, existing palliative care models are not suitable for older people because they need both palliative and geriatric care.[2] Palliative care for the older population is different from younger people because of the nature and duration of illness conditions during old age.[7] Four main specific issues of palliative care for older people are geriatric syndromes,[20] pharmacologic management of pain in the elderly,[21] development of elderly in psychosocial aspect,[22] and having multiple diseases and being long periods.[2]

Therefore, providing care for older people with cancer is challenging because physiologic changes with aging and co-morbidities affect the ability to tolerate treatment and recover following treatment. Co-morbidities generally occur before a person is diagnosed with cancer and are exacerbated during treatment, or are the consequence of treatment. Body systems are often affected by cancer treatment or preexisting comorbidities, such as visual, auditory, endocrine, cardiac, pulmonary, gastrointestinal, urologic, and neurologic systems.[23,24]

Older people may gradually deteriorate with some periods of rapid decline. The frail elderly and dementia/Alzheimer's disease groups have a low level of functioning in activities of daily living and show a progressive decrease in physical ability in the final year of their life. However, this trajectory may be cut short by death after an acute situation such as a fractured femur or pneumonia. Additionally, people with dementia who die suddenly,[25] usually have not been recognized as being in the final stage of life and thus in need of palliative care,[24] especially in the home.

Palliative care provided in the home setting is associated with a reduction in symptom burden and increases older people and their family caregivers' satisfaction.[25] Home care can provide an opportunity for family caregivers to learn and develop specific knowledge, attitudes, and skills within the home environment. However, palliative care in home settings is generally provided without training, particularly in rural areas.

Systematic reviews emphasize that people prefer to be cared for at home.[4,13,26,27] Accordingly health care services must support those preferring to stay at home in the last phase of their lives. Increasing time at home can often be a more realistic objective for home-based palliative care than home death, as it says something about the extent to which people desire to live out their lives at home.

The WHO[5] has argued that families must become progressively involved as care partners of their relatives. At the same time, however, the aging of populations means family caregivers will themselves increasingly become recipients of care. Health care providers face the challenge of supporting and improving the family's capability to care for older people in the palliative care stage at home.

Globally there is strong evidence of the challenges that family caregivers face in providing care. They are frequently unprepared to assume the role of caregiver and to deal with several changes and difficulties implicated in this role.[27] For example, family caregivers feel exhausted, distressed, and need support to carry out care at home. Many studies reported that most family caregivers are unpaid for their work and caregiving is detrimental to their health. In addition, they need to provide emotional support, intimate care, and direct hands-on care.

Providing care for older people at home increases family caregivers' sense of security, fostering their sense of control, inner peace, and dignity, but while psychosocial needs are often unrecognized and unsatisfied, family resources may address overwhelming responsibility, fear, loneliness, and death anxiety.[26] When the life of their relative is threatened, families feel often feel more satisfied to live the last days with their loved one in the manner and in the place they prefer. This is the time when all the health care providers' actions should be thought out and tailored according to families' needs.[26-28]

Studies related to family caregivers identify a considerable level of need.[13] Thus, it is important to understand family caregivers' needs when they act within the home environment. Appropriate care for older people in palliative care at home requires culturally competent care of the whole person with coordination among healthcare providers because this is a vulnerable population with a unique set of needs.

Aim

This study aimed to explore Thai family caregivers' perceptions of caring for older people who are in the palliative care stage at home.

Methods

Design: This study utilized a qualitative approach to explore the experiences of family caregivers' perceptions on caring for older persons in the palliative care stage at home. This report follows the Consolidated Criteria for Reporting Qualitative Studies (COREQ).

Using purposive selection, the researcher selected individuals for study participation based on their perception of the phenomenon to share that experience of caring for their loved one.[29] Perceptions were shared through in-depth interviews from caregivers who caring older persons in the palliative care stage at home. This approach was selected to enable the researcher to gather, analyze and interpret the perceptions of care, realities, and meaning from the participants in this research in a way that is culturally appropriate and uses subjective perceptions of their lives to construct knowledge and build understanding on this research question.[30]

Sample and Setting: The research was conducted at the older persons' homes located in Hat Yai, Songkhla Province, southern Thailand. The participants had been receiving care services from the local primary care centers via a long-term care service system. Purposive sampling was used to select the participants. The number of participants depended on the saturation of the emerged data on nursing care activities. The inclusion criteria of the participants were as follows:

Older persons: Being Thai; 60 years of age or over and living with a terminal illness (determined by the Palliative Performance Scale, PPS less than or equal to 50%) in one of three groups: cancer stage III through to IV, end-stage organ failure and prolonged living with frailty, moderate or severe dementia, or Alzheimer's disease.

Family caregivers: Being Thai; older than 18 thus able to give informed consent; being a family caregiver of an older person at home (relative or partner); providing care during the study and willing to continue care for the older person; and able to understand the Thai language.

Exclusion criteria:

Older people: having a palliative care consultation during hospitalization before the study; no known family or a surrogate decision-maker; death expected within 24 hours; or deceased during data collection.

Caregivers: non-formal caregivers; unable to communicate in Thai; and receiving formal diagnosis of major psychiatric disorders.

Participants were recruited by the following procedure: The registered nurse who served as a designated contact at each primary care center was introduced to the research project, objectives, and the participants' recruitment criteria. Then, the researchers reviewed the name list and medical records to gather basic information about the older people and their family caregivers who met the criteria and could potentially be selected as participants. These individuals were invited to participate in the study by phone. An interview appointment along with permission to visit their homes was obtained.

Ethical considerations: Ethical approval was granted by the Institutional Review Board of the Faculty of Nursing, Prince of Songkla University (PSU IRB 2017-NSt 003). Permission for the study was granted by the health authority of the Hat-Yai Municipality Following a screening, informed written consent was obtained from each of the participants who met the inclusion criteria and were willing to participate in this study. Each participant was also assured of confidentiality and the voluntary nature of the study. The participants had the option to decline or withdraw from the study at any time and were guaranteed anonymity in the published results.

Data collection: The interviews were conducted using a semi-structured interview guide developed by all of the researchers and validated by three experts (an advanced practice nurse in palliative care and two nurse lecturers with expertise in palliative care and advanced qualitative research). The questions in the interview guide addressed participants' experiences and thoughts for the family caregivers about caregiving. Examples of questions asked were: How do you feel about caring for the older people in this stage?; How do you provide care?; What are the problems/obstacles?; What are the supports available?; and How do you manage? This study was carried out from May to December 2017. The family members shared their perceptions on care needs for their relatives.

The interviews were audio-recorded after consent from the participants. Twelve visits were scheduled to interview the caregivers in their homes. Each interview took about 60-90 minutes. The participants were visited weekly, however, the times of follow-up were depending on the situation and data saturation. All participants have visited an average of 12 times. The demographic data about the participants were collected by a questionnaire filled in by the participants before the start of the interview.

Data analysis: All interviews were digitally recorded and transcribed verbatim in Thai soon after the interviewing sessions. The researcher carefully read the transcript word by word to gain a sense of the whole data. The next step involved breaking the data into analytic units, coding each of the units, naming the units, and grouping categories into a hierarchical structure. Content analysis was used to analyze the data[29] to understand the situations, participants' perspectives, cultural norms, and other pertinent problems in the field. The process of this analysis helped the researcher to obtain the participants' perspectives to improve care for older people. Three experts then proofread the transcript to check the validity of translation from southern Thai dialect to formal Thai language.

Observation of care activities and interactions with the family caregivers were made during the interviews and in many visits by the researcher. The interview transcript was translated into English by the researcher then edited by a native English speaker for grammatical accuracy. After analyzing the data, member checking was used by which findings were presented to the participants for further review and reflection to ensure qualitative research rigor. Content analysis was also undertaken on the field notes.

Trustworthiness: This was evaluated following the four criteria for qualitative research: credibility, transferability, dependability, and conformability.[29] Firstly, credibility was established using four methods: prolonged engagement by visiting the participants weekly which average 12 times, taking about 60-90 minutes for each interview, conducting triangulation (in-depth interview, a questionnaire, observation, and playing back the audio-recordings), member checking, and peer-debriefing. Secondly, the transferability of the study's findings was ensured by a 'thick description' of the participants, the context, and the entire study process. Thick description means that data has been collected with a sufficiently detailed description of the methodology and reported with enough detail and precision that allow a judgment to be made by the reader. Thirdly, dependability was guaranteed by an audit trail. All data from digital recordings, transcription, and field notes were analyzed and documented to ensure accuracy as well as to facilitate the audit trail. Finally, member checking was performed, and findings were explained to the participants. All information was recorded in an orderly and clear manner to confirm understanding among the participants.

Findings

Characteristics of the participants

Among the ten older participants (see **Table 1**), there were five men and five women, ages 60-91. All of them were Buddhists. The older participants could be divided into two groups: patients with cancer (lung, breast, ovarian) and patients without cancer (COPD, renal failure, CVA, diabetes, frailty, and dementia/Alzheimer).

Table 1 Characteristics of the older persons (n = 10)

Characteristics		**n**
Gender	Male	5
	Female	5
Age (years)	60-70	5
	> 70-80	4
	> 80	1
Religion	Buddhist	10
Health problems	Cancer (lung, breast, ovarian)	3
	End-stage of organ failure (COPD, renal failure, CVA, diabetes)	4
	Frailty and dementia/Alzheimer	3
Marital status	Single	1
	Married	4
	Divorced/widowed/separated	5
Education	No formal education	1
	Elementary	8
	Bachelor degree	1
Family monthly income (Baht)	5,000 -10,000 (US$ 150-300)	4
	>10,000-20,000 (US$ > 300-600)	1
	>20,00-30,000 (US$ > 600-900)	2
	>30,000 (US$ > 900)	3
Health insurance	Universal health care coverage	9
	Social security	1

Among the ten family caregivers (see **Table 2**), there were four men and six women, ages 38-75. All of them were Buddhists. Seven family caregivers were older persons themselves. Most of the caregivers were spouses (3 cases), siblings (3 cases), or adult children (3 cases). More than half (6 cases) of the family caregivers were women.

Table 2 Characteristics of the family caregivers (n = 10)

Characteristics		n
Gender	Male	4
	Female	6
Age (years)	<60	3
	60-70	4
	>70	3
Religion	Buddhist	10
Relationship with the elderly	Spouse (husband=2, wife=1)	3
	Adult child (son=1, daughter=2)	3
	Sibling (older sister=1, younger sister=2)	3
	Grandson	1
Marital status	Single	2
	Married	7
	Widowed	1
Education	Elementary	6
	Bachelor degree	3
	Master degree	1
Occupational status	Unemployed	8
	Business person	2

Themes

Two themes were identified: 1) recognizing limitations in the ability to provide care and 2) feeling burdened by caregiving.

Theme 1: Recognizing limitations in the ability to provide care

Four caregivers were three adult children and one grandson. They expressed that caregiving for their loved ones led them to recognize they sometimes felt incapable of caregiving because caring for the older persons was providing loving care and repaying the kindness to the elder. Thus, they provided care with willingness. However, during the care provided, the main concerns of the caregivers were as follows: 1) concerns about infection or complication, and 2) feeling insecure due to lacking adequate caregiving skills.

Sub-theme 1: Concerns about infection or complication

Some caregivers were anxious to prevent infection that could occur in the older family member because they had been informed that the infection leads to many symptoms, even early death. One caregiver reflected:

> *"I want to change my house, so it looks cleaner. I hire a cleaner to clean my house once a week. I'm afraid my father will be infected because he has a tracheostomy tube. I cannot manage to maintain a clean house, because we are living with my brother who is a psychiatric patient. I cannot resolve the conditions. I have been with him since childhood; I have not changed much. I have to live this way."* (A 38-year-old man, caregiver of a 66-year-old father with CVA)

> *"Why would changing his left nasogastric tube produce more secretion than changing the right side? Every time, it is always early I worry about the secretion. What effect might it have?"* (A 38-year-old man, caregiver of a 66-year-old father with CVA)

Sub-theme 2: Feeling insecure due to lacking adequate caregiving skills

Even though the caregivers might have already provided complete care, they still needed to learn proper care for the older person. Some older family members and their caregivers were unable to manage symptoms or comfort.

> *"I do not know what to do when she has symptoms such as severe pain and dyspnea. I quickly take her to the hospital."* (A 66-year-old man, caregiver of a 68-year-old wife with lung cancer)

Theme 2: Feeling burdened by caregiving

Feeling burdened by caregiving included the inability to maintain social activities, inability to maintain daily activities, deterioration of health, and inability to execute the elderly's end-of-life wishes. For some of the caregivers in the group, the role of the caregiver was unacceptable. They did not modify their self-concept as a caregiver for older people. Six caregivers were a spouse or a sibling. All of them were elderly and had illnesses themselves. They were unwilling to provide care for the elderly family member or take on the role of caregiver. They had feelings of being burdened by caregiving which resulted in four sub-themes: inability to maintain social activities, inability to maintain daily activities, deterioration of health, and inability to execute their relative's end-of-life wishes.

Sub-theme 1: Inability to maintain social activities

Providing care reduced the social activities of the caregivers. Care responsibilities might force them to give up some of the social activities they previously enjoyed, which made them feel isolated from typical social events such as meeting friends, making merit, and traveling. Caregivers needed to find ways to participate in some of their previous social engagements. Two caregivers reflected:

> *"I cannot go anywhere or take part in social outings. My friend invited me to make merit on a tour program but I cannot."* (A 72-year-old woman, caregiver of a 66-year-old brother with CVA)

> *"In the past, I always offered food to monks and made merit at the temple, but now I cannot do this. It's stressful because I cannot go to places I need to go."* (A 70-year-old woman, caregiver of a 75-year-old husband with dementia)

Sub-theme 2: Inability to maintain daily activities

Five of the caregivers lived with other family members, while one lived with the older person to whom the care was provided. All provided care by themselves. Their care routines included hygiene care, dressing, feeding, preparing food, cooking, and housekeeping (e.g. washing clothes and cleaning the home). As two caregivers explained:

> *"I have to do all the housekeeping. Other family members cannot help to care for the older person or the housekeeping. I suffer severe pain from osteoporosis in my back and my legs. I do not know what day I will die."* (A 72-year- old woman, caregiver of a 66-year-old brother with CVA)

> *"I am overwhelmed because of his kidney dialysis after which I saw the clock and realized oh time passes quickly. Then I have to wash the dialysis towel."* (A 71-year-old woman, caregiver of a 63-year-old husband with renal failure)

Sub-theme 3: Deterioration of health

Most caregivers were older adults who suffered from chronic diseases and health deterioration due to aging. Caregivers of the older people worked hard and often did not get enough rest. As a result, providing care for older persons adversely impacted the caregivers' health: having physical problems and having mental distress.

Providing care for the older persons around the clock exacerbated caregivers' illnesses such as high blood pressure and osteoporosis pain. As three caregivers explained:

> *"I once was healthy, but since my brother became dependent on my care I feel weak, sick, uncomfortable, dizzy. I suffer from pain in my back/legs and my body. I have chronic diseases: diabetes mellitus, hypertension, and osteoporosis."* (A 75-year-old woman, caregiver of a 66-year-old brother with CVA)

> *"I rarely walk; my legs are bending so I cannot walk. If I am healthy, I would be able to help and provide care for him fully."* (A 71-year-old woman, caregiver of a 63-year-old husband with renal failure)

> *"I have pain in my chest and back because I have to lift him. Five months ago, I could not raise my hand because of edema and severe pain."* (A 42-year-old woman, the caregiver of a 74-year-old father with COPD)

The caregivers had not fully accepted the caregiving role. Most explained that the role was unfairly assigned by other family members who were not willing to participate in this role. Mental distress was found in the caregivers such as depression and stress. For example, two caregivers explained:

> *"I have hypertension yet I must provide care for him. Sometimes I feel overwhelmed and think of providing for the older person is a burden. I need someone else to take a turn and help. Sometimes, I have suicidal thoughts."* (A 72-year-old woman, caregiver for a 77-year-old husband with dementia)

> *"Our life is tough, we have no children. My husband and I help each other. This obstacle is like a canal that we must swim across, even if I cannot swim but I have to try."* (A 71-year-old woman, caregiver of a 63-year-old husband with renal failure)

Sub-theme 4: Inability to execute the elderly's end-of-life wishes

Even though the family caregivers understood completely that they ought to fulfill the older member's wishes at the end of life, some found it difficult to understand or accept these wishes. In particular, when dealing with advanced directive treatment that the older adults might have ordered, some family members could not accept this. This issue caused family conflict. Family members opposing the advanced directive prevented the older member's end-of-life wishes to be heard. As caregivers explained:

> *"His hand is tied; a tracheostomy tube and nasogastric tube were placed and he has intravascular injections. My sister did not agree with me on these treatments; she is afraid Dad would suffer. But he has severe symptoms, I feel sorrow."* (A 42-year-old woman, caregiver of a 74-year-old father with COPD)

Discussion

This study explored the perception of family caregivers to care for older people in the palliative care stage at home. The findings contribute to the understanding of providing care to their loved ones based on their experiences and perceptions. Two themes found in this can be explained as follows:

Recognizing limitations in the ability to provide care

Most participants were adult children and expressed that they cared for their seniors to repay their kindness. The role of a child in a Thai family focuses on expressing their gratitude. In addition, they cared for their loved ones by providing unconditional care by love. However, most of them lacked specific knowledge and caregiving skills to provide palliative care for older people.

The caregiving role for older people with palliative care needs is learnt secondary. The role can be acquired through learning caring skills responding to the care requirements.[26] The caregiver role assists the older person by helping everyday in bog tasks. They understand they need to provide comfort and dignity to their loved one at the end-of-life phase. The role of family caregivers involves continual problem solving, decision making, communication with others (family members and health care providers), and constant vigilance over the care of their loved one's well-being.[26]

Developing caregiving skills can improve symptoms, and it has the potential to decrease the caregiving burden related to role changes and improve caregiver quality of life.[31] In addition, caregiving skills can improve caregiver knowledge, confidence, and self-efficacy, in turn, benefits both caregivers and patients.[32] Improved knowledge, support, and understanding of disease progression, medication, and symptom management, warning signs, complications prevention, and resources available may help to empower family caregivers' actions. The removal of these barriers may support family caregivers when seeking help. In addition, family caregivers need advice on how or when to provide care or what devices to use in their caregiving role. Nurses have the opportunity to explain or share information about the awareness of the risk of complications. Health care providers can deliver training to increase caregivers' confidence, prevent complications and burnout.[13,26,32]

This theme is congruent with the study of Teixeira and colleagues[14] whose study revealed increases in caregiver activity, caregiving preparedness, and family confidence. Lia and colleagues [33] conducted a skills training program for the family caregivers of dementia people. The evaluation showed improvement in distress and quality of life compared to the control group. Another result found that caregivers had better outcomes in bodily pain, role disability due to emotional problems, vitality, mental summary score, and reduced risk for depression.

However, some caregivers in this study felt they were losing their role. For example, they left a job to take care of their loved ones and some caregivers maintained both caregivers' roles and occupational roles together. Even all family members agreed that this person was the most suitable to provide for the elderly but some caregivers were not willing to accept in their role.

Feeling burdened by caregiving

The burden is commonly understood to be composed of both objective and subjective components. The objective burden often refers to events and activities associated with negative caregiving experiences, whereas the subjective burden is the emotional reaction of the caregiver such as worry, anxiety, and fatigue.[33] There are many studies and reports about care burden. If an older person needs palliative care at home, then family caregivers must provide heavy care for that person for they have severe impairment all day.[34]

The family care burden is usually found in older caregivers, who most often have health problems and chronic diseases such as hypertension and osteoporosis. Health problems were caused by the caregiving itself, such as back pain and chest pain. They believed the care burden impacted the quality of care because they undertook caregiver roles that involved overwork. This result is consistent with the study of Teixeira and colleagues[14] who found that family caregivers have health problems, the most prevalent of which are physical problems of sleep disturbance, fatigue, pain, loss of physical strength, loss of appetite, and weight loss. In addition, in our study, we also found that caregivers had a lack of time. They needed respite care or other family members to take a share of the burden so they could undertake shopping, traveling, or making merit.

Mental distress was found in caregivers including depression and stress. Stress is a multifactorial, unpleasant emotional experience of psychological (cognitive, behavioral, emotional),[33] social and/or spiritual nature that may interfere with effective coping,[31] About 41-62% of family caregivers providing palliative care had a high level of psychological distress compared with 19% of the general population.[34]

Many studies have identified the difficulties facing family caregivers in providing palliative care for persons with late-stage cancer at home. There are typical difficulties such as that of treatment in emergencies and spiritual pains.[35,36] Nagata and colleagues[35] reported that family caregivers who provide palliative care at home experience a different situation than other caregivers.

Study Limitations

This study was conducted in only one province of Thailand, and all older people and their family caregivers were Buddhist. Hence, caution should be taken in other populations and other cultures. The participants in this study are a valuable population and their experiences must be understood with sensitivity to human rights and realizing the uniqueness of Thai culture. Talking about death and dying in Thai society has not been easy. This is a challenging task for healthcare providers to carry out in Thai culture where discussion about death and dying could be seen as a taboo topic. In the limited in-depth interview discussion, family caregivers faced difficulty in discontinuing from providing care to the older person. In addition, we had a great deal of verbal and nonverbal data which was challenging to confirm and summarize and which should be investigated further.

Conclusion and Implications for Nursing Practice

This study provides detailed perceptions of family caregivers when caring for older people in the palliative care stage at home. Family caregivers of older people are required to gain knowledge about the caregiving role and prevention of complications with their own needs. The themes that emerged from this study can help to develop nursing care activities to meet specific needs and can also impact the quality of care and reduce the caregiving burden. The study findings assist nurses in primary care centers in providing for the elderly with being at the palliative care stage at home and their family caregivers in Thai culture. It is encouraged that primary care centers, as well as nursing education, need to provide education and support to allow nurses to apply palliative care principles and practices and teach patients and caregivers via long-term care service system to visit home. In nursing education, academics can use the knowledge of perceptions of family caregivers and at home palliative care theory to enable nurses to practice in the community and society. In addition, nurse managers in hospitals and directors in primary care centers can encourage their colleagues to improve their knowledge on palliative care at home regarding perceptions of family caregivers to care for the elderly in the palliative care stage at home. The health care provider needs to be trained to enhance their knowledge and skills of palliative care, which can then be applied to the knowledge in the area appropriate for improving service quality and patients' quality of life.

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Conflict of Interest Statement

The authors declare no conflict of interest.

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การรับรู้ของครอบครัวผู้ดูแลผู้สูงอายุในระยะประคับประคองชีวิตที่บ้าน

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บทคัดย่อ: การดูแลแบบประคับประคองที่บ้านสำหรับผู้สูงอายุในบริบทของครอบครัวเป็นหนึ่งในความท้าทายของโลกและสังคมไทยปัจจุบัน รูปแบบการดูแลแบบประคับประคองที่มีอยู่ยังไม่เหมาะสำหรับผู้สูงอายุซึ่งต้องการทั้งการดูแลแบบประคับประคองและการดูแลที่เฉพาะกับผู้สูงอายุ ซึ่งมีแตกต่างจากคนที่อายุน้อยกว่า เนื่องจากลักษณะและระยะเวลาของการเจ็บป่วยในวัยชรา ดังนั้น ภาระการดูแลที่หนักหน่วงจึงตกอยู่กับครอบครัวผู้ดูแลซึ่งทำหน้าที่สำคัญในการดูแลผู้สูงอายุทั้งหมด การศึกษานี้มีวัตถุประสงค์เพื่อศึกษาการรับรู้ของครอบครัวผู้ดูแลผู้สูงอายุในระยะประคับประคองที่บ้าน โดยใช้กระบวนการวิจัยเชิงคุณภาพแบบพรรณนา ผู้เข้าร่วมวิจัยเป็นครอบครัวผู้ดูแลผู้สูงอายุระยะประคับประคองที่บ้านจำนวน 10 ราย ที่อาศัยอยู่ในเขตเทศบาลนครหาดใหญ่ สงขลา ซึ่งเป็นจังหวัดหนึ่งในภาคใต้ของไทย วิเคราะห์ข้อมูลโดยใช้การวิเคราะห์เนื้อหา การรับรู้ของครอบครัวผู้ดูแลที่พบมี 2 ประเด็นหลัก ได้แก่ 1) ตระหนักถึงข้อจำกัดในความสามารถในการให้การดูแล และ 2) รู้สึกเป็นภาระในการดูแล ผลการวิจัยนี้ช่วยเพิ่มความเข้าใจให้แก่ผู้ให้บริการด้านสุขภาพและบุคคลทั่วไปเกี่ยวกับการรับรู้ของสมาชิกในครอบครัวที่ดูแลผู้สูงอายุในระยะประคับประคองที่บ้าน ระบบบริการสุขภาพระดับปฐมภูมิและการศึกษาพยาบาลควรให้ความรู้และช่วยเหลือพยาบาลในการปฏิบัติตามแนวทางการดูแลแบบประคับประคองที่เหมาะสม เพื่อช่วยเหลือผู้ดูแลผู้สูงอายุกลุ่มนี้ที่บ้าน ซึ่งจะช่วยให้พยาบาลมีทักษะและความรู้ที่เหมาะสมในการยกระดับคุณภาพการดูแลและคุณภาพชีวิตของผู้สูงอายุและผู้ดูแล

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คำสำคัญ: ผู้สูงอายุ ผู้ดูแล การดูแลที่บ้าน การดูแลแบบประคับประคอง

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